

Knowledge, Attitudes, and Behavioral Intentions toward Those with Lyme Disease

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Abstract

Three hundred sixty-two undergraduates attending college in Michigan or West Virginia responded to a survey measuring their knowledge about Lyme disease, and their attitudes and behavioral intentions toward those with Lyme. Women, those who knew something about Lyme disease, and those who knew someone with Lyme disease showed the most knowledge, most favorable attitudes, and most positive behavioral intent. Those from a college in an area with a greater risk for contracting Lyme disease had greater knowledge than those from colleges in a lower-risk area. Knowledge, attitude, and behavioral intent scores all correlated significantly. These results add to research into the socio-psychological impact of the disease, especially in its chronic manifestation. Greater focus on the gender manifestations of responses to Lyme disease, and on the differences between the responses of the medical community and the general public is suggested.

Keywords: chronic Lyme disease, knowledge about Lyme disease

1. Introduction

Lyme disease, caused by the spirochetal *Borrelia burgdorferi* bacterium, is the most prevalent vector-borne disease in the United States and Europe (Kurnatowski Warpechowska, & Kurnatowska, 2011), accounting for about 300,000 cases diagnosed in the United States each year (CDC, 2013). To date, social science research focuses mostly on education and prevention strategies and response to treatment among those most likely to contract the Lyme infection. For instance, studies of knowledge about Lyme disease suggest that many people in certain, especially endemic, areas are well-versed in the cause, early symptoms, and behaviors that put one at risk for contracting the Lyme infection. Almost 100% of a sample of well-educated New England residents from Block Island and the University of Connecticut knew that Lyme disease was transmitted by a deer tick, caused a rash and joint pain, and that walking through the woods off trail and in a field of high grass put one at risk of picking up a deer tick (Closter, Erickson, Krause, Macaуда, Mann, & Miller, 2011). Likewise, nearly 100% of foresters, university students, and secondary students in Poland knew that Lyme infection was contracted via tick bites, a majority correctly identified effective prevention strategies, and most of the older participants had been tested for the infection (Kurnatowski, et al., 2011).

In a study of the impact of community-based education and prevention programs, most residents in an endemic area of Connecticut knew about Lyme infection and what they could do to help avoid getting it. They were willing to engage in *some* personal prevention behaviors (wearing tick repellent and checking for ticks after being outside), but not others (tucking their pants into their socks and staying out of the woods) (Cartter, Gould, Griffith, Hayes, Mead, & Nelson, 2008). However, members of an immigrant population living in an endemic area were not sufficiently knowledgeable about Lyme disease, their risk for contracting it, and what they could do to help avoid becoming infected (Heller, Benito-Garcia, Maher, Chibnik, Maher, & Shadick, 2010).

A study of a sample of the general public living in the Netherlands (Beaujean, Bults, van Steenbergen, & Voeten, 2013) helped identify factors other than immigrant status that may be related to Lyme knowledge and prevention. They found that preventative behaviors such as checking for ticks, wearing protective clothing, and using tick repellent were positively related one's level of knowledge about Lyme infection, the degree to which one believes preventative strategies will be effective, and the degree to which one is worried about contracting Lyme disease. Among children aged 9-13 in the Netherlands, those who knew someone who had gotten sick after a tick bite were more knowledgeable about Lyme and more likely to take effective precautions themselves. Children who accurately assessed their risk for Lyme disease were also more likely to report checking themselves or being checked for ticks after being outside (Beaujean, Gassner, Wong, van Steenbergen, Crutzen, & Ruwaard, 2013).

Typically, if diagnosed early, Lyme infection results in a rather mild reaction that responds to the standard course of antibiotic treatment of two to four weeks, which can be repeated once (Closter et al., 2011). However, symptoms of the Lyme infection are suggestive rather than definitive, and there is no blood test for convincingly diagnosing (or ruling out) Lyme infection (Drew & Hewitt, 2006), making early and medically convincing diagnosis and treatment of Lyme infection problematic.

Although most people recover quickly from Lyme infection with no long-lasting effects, 10-20% of people diagnosed with Lyme disease report chronic, debilitating symptoms of Lyme infection long after the standard treatment is completed, a syndrome typically referred to as "chronic Lyme disease" or "Post-treatment Lyme disease Syndrome (PTLDS)" (CDC, 2014). Many in the medical community are skeptical of the chronic diagnoses; the Centers for Disease Control, the National Institutes of Health, and the Infectious Diseases Society of America all recommend limiting the use of antibiotics to two months; and long-term antibiotic use risks significant adverse reactions (Cartter et al., 2008). Reporting is also impacted by the one reporting the infection. In Connecticut, physician-reported cases of Lyme disease were significantly more likely to occur in the summer and to have the characteristic bull's-eye rash (erythema migrans). Cases reported through laboratories, however, had a later manifestation (or recognition) and were cases which were more long-standing (Ertel, Nelson, & Cartter, 2012).

Interestingly, the majority of a sample of members of the general public living in a Lyme-endemic area believed that Lyme infection can persist after antibiotic treatment and that additional treatment would be beneficial. Almost two-thirds of respondents said that their source of information about the course of Lyme infection and the possibility of long-term, antibiotic-resistant symptoms came from those whom they knew with the infection (Closter et al., 2011). Participants from Poland, when asked to identify symptoms of Lyme disease, frequently mentioned both early-onset and late-stage symptoms (myalgia, arthritis, rheumatoid changes, and myocarditis) of the infection. Overall, the most common source of information about the infection for those participants was also friends, with other commonly-identified sources of information being the internet, teachers, and medical personnel (Kurnatowski, et al., 2011).

Faced with frustratingly-persistent symptoms and a medical community that may be dismissive, patients with chronic Lyme symptoms, at least in the United States, face additional obstacles to health. In a qualitative, interview-based study of people diagnosed with chronic Lyme disease, Drew and Hewitt (2006) found that six themes emerged: frustration, delayed diagnosis, financial stress, need for self-advocacy, validation when the diagnosis occurred, and a sense of hopefulness for the future. Ali, Vitulano, Lee, Weiss, and Colson (2014) found some similar results in their qualitative study of patients self-identified or medically-diagnosed with chronic Lyme disease. While experiencing chronic Lyme, their participants reported a decline in their health status and quality of life; doubts that they would ever fully recover; contact with some supportive physicians and with some physicians who were condescending, patronizing, and dismissive of the diagnosis; and use of alternative medical providers and treatments.

Clearly, knowing someone with chronic Lyme disease changes how one thinks about it. What is largely missing from the literature are studies of how much people in general, especially those from non-endemic areas, know about Lyme disease, their attitudes toward those with Lyme disease, and their behavioral intentions toward those with Lyme disease. The purpose of our study was to investigate more fully the relationships between individuals' knowledge about Lyme disease, and their attitudes and behavioral intentions toward those with Lyme disease. Because most of those troubled by Lyme disease are those whose symptoms have not abated after standard medical treatment, our focus is on discovering how the knowledge, attitudes, and behaviors of the non-medical public may impact those with chronic Lyme disease.

2. Method

2.1. Participants

Participants were 362 student volunteers attending Michigan (79%) and West Virginia colleges (21%). Ninety-eight percent of respondents were between the ages of 18 and 23; 73% were female; and 92% were white, non-Hispanic. Fifteen percent were from urban areas, 46% from suburban areas, and 39% from rural areas. Participants were approximately equally distributed across year in college. Forty-four percent were natural science majors, 31% were social science majors, 19% were humanities majors, and 6% were undecided. Most of the students attending the Michigan college were from Michigan, and most of the students attending the West Virginia colleges were West Virginia, Ohio, or Pennsylvania residents. Institutional Review Boards at all three colleges approved the project.

Participants were recruited via restricted e-mail, advertisements on the college-restricted web portal, and class announcements. Participants completed the survey individually, on paper or via SurveyMonkey, with some students receiving research credit for participating or the opportunity to enter a drawing to win one of five gift cards. Students were asked a number of demographic questions, including whether or not they had contracted Lyme disease themselves or knew someone who had.

2.2 Materials

Knowledge of Lyme facts was measured with fifteen multiple choice and true/false questions based on accepted facts about Lyme disease (Vanderhoof-Forschner, 2003). Examples of these items included: (multiple choice) *How is Lyme disease transmitted? a. sharing a toilet seat with an infected person, b. being bitten by an infected tick, c. kissing an infected person, d. changing the diapers of an infected child; What is the best treatment for Lyme disease? a. antibiotic therapy, b. antiviral therapy; c. chelation therapy, d. time, rest, and plenty of fluids;* and (true or false) *Lyme disease is caused by a virus; Wearing a hat and tucking your pants into your socks is an effective way to help prevent Lyme disease.* Attitudes and behavioral intentions about Lyme disease and toward people with Lyme disease were each assessed with twenty items that participants rated on a five-point Likert scale. These items were adapted from surveys related to other diseases and disabilities (Christison, Haviland, & Riggs, 2002), then scored so that higher scores indicated more favorable attitudes and behavioral intentions toward those with Lyme disease. Examples of these survey items included: (attitudes) *People with Lyme disease use their illness as an excuse to get special treatment; I feel compassionate toward people with Lyme disease;* and (behavioral intentions) *I would be willing to perform mouth-to-mouth resuscitation on a person with Lyme disease who was in respiratory arrest; I would be willing to do volunteer or advocacy work to help people with Lyme disease.* Knowledge, attitude, and behavioral intention items were mixed together throughout the survey.

3. Results

Mean scores on the survey items showed that overall, participants had a moderate level of knowledge about Lyme disease ($M = 9.71$ (out of 15), $SD = 2.19$), and had generally favorable attitudes ($M = 74.74$ (out of 100), $SD = 10.73$) and positive behavioral intentions ($M = 76.17$ (out of 100), $SD = 12.57$) toward those with Lyme disease.

Women had significantly greater knowledge about Lyme disease, $t(356) = 2.75$, $p = .006$ (women $M = 9.90$, $SD = 2.10$; men $M = 9.19$, $SD = 2.37$); more favorable attitudes toward those with Lyme disease, $t(356) = 3.43$, $p < .001$ (women $M = 75.86$, $SD = 10.14$; men $M = 71.51$, $SD = 11.73$); and more positive behavioral intentions toward those with Lyme disease, $t(356) = 3.20$, $p < .001$ (women $M = 77.41$, $SD = 11.25$; men $M = 72.65$, $SD = 15.26$), than did men. Those from the Michigan college had greater knowledge about Lyme disease than those from the West Virginia colleges, $F(2, 358) = 4.45$, $p = .012$ (Michigan $M = 9.98$, $SD = 2.19$; West Virginia college 1: $M = 8.85$, $SD = 2.32$; West Virginia college 2: $M = 9.19$, $SD = 1.94$).

Participants who said they knew some or a little about Lyme had significantly more favorable attitude scores than those who said they knew nothing, $F(3, 357) = 6.01, p < .001$ (some: $M = 78.08, SD = 11.72$; a little: $M = 75.76, SD = 9.87$; nothing: $M = 71.79, SD = 10.57$). Those who said they knew some about Lyme disease had significantly more positive behavioral intent scores than those who said they knew a little, and those who said they knew a little had significantly higher scores than those who said they knew nothing, $F(3, 357) = 11.98, p < .001$ (some: $M = 81.65, SD = 12.39$; a little: $M = 77.72, SD = 11.32$; nothing: $M = 71.43, SD = 12.68$).

Participants who knew someone with Lyme disease had significantly more favorable attitude scores, $F(2, 354) = 7.02, p < .001$, and significantly more favorable behavioral intention, $F(2, 354) = 5.51, p = 0.004$, than participants who did *not* know someone with Lyme or did not know if they did (attitudes: knew: $M = 78.64, SD = 11.49$; did not know: $M = 74.08, SD = 10.58$; unsure: $M = 71.89, SD = 8.41$) (behavioral intent: knew: $M = 80.42, SD = 13.16$; did not know: $M = 75.21, SD = 12.50$; unsure: $M = 74.42, SD = 10.72$).

Knowledge and attitude scores were significantly positively correlated ($r(360) = .41, p < .001$), as were knowledge and behavioral intention scores ($r(360) = 0.45, p < .001$), and attitude and behavioral intention scores ($r(360) = 0.89, p < .001$).

4. Discussion

Previous research shows that a common source of information about Lyme disease is friends and acquaintances with the disease (Closter et al., 2011, Kurnatowski, et al., 2011). Those who are ill for long periods of time can feel like a burden, fearing that others may have negative feelings about them (Cousineau, McDowell, Hotz, & Hebert, 2003). Our study, however, shows that within the non-medical community, those who know someone with Lyme disease, presumably someone with chronic Lyme disease, have more favorable attitudes and more positive behavioral intentions toward those with Lyme disease than those who do not know someone with Lyme disease. Additionally, in our study, *more* knowledge is associated with *more* positive attitudes and behavioral intentions. Perhaps this finding can help encourage Lyme patients to share their stories with others, with confidence that they will be met with positive attitudes and behaviors among the general public. Those who continue to have symptoms after standard treatment can help others become more familiar with the manifestations of chronic Lyme disease.

Using the Centers for Disease Control health-related quality of life indicators, Johnson, Wilcox, Mankoff, and Stricker (2014) compared chronic Lyme disease patients to a sample of the general population and to a sample of people with other chronic illnesses. Compared to these two groups, chronic Lyme disease patients reported a significantly poorer health status, had more bad physical and mental health days, used the health care system more often and incurred more medical expenses, and had greater limitations on their level of activity and ability to work than either of the other groups.

In addition, those with chronic Lyme disease often report negative interactions with the medical community and skepticism about their diagnosis in the medical literature (Drew & Hewitt, 2006; Ali, et al., 2014). Both the feelings of being a burden and the negative interactions with medical personnel might be explained in part by gender expectations. There are significantly more women than men diagnosed with chronic Lyme disease (Wormer & Shapiro, 2009). In our study, most of the participants were women, and women evidenced greater knowledge about Lyme disease, more favorable attitudes towards those with Lyme, and more favorable behavioral intentions toward those with Lyme than did men. Any discussion about people's attitudes toward Lyme patients and the treatment of Lyme patients would be wise to consider the gender dimensions of the illness and the issues surrounding it, as well as the differences in responses between the medical community and the general public.

The knowledge, attitudes, and behaviors of others can greatly impact the quality of life of those with Lyme, as well as their success in getting well. Consequently, studying these factors has important real-life consequences. When we find that knowledge, attitudes, and behavioral intentions regarding Lyme disease do, in fact, positively correlate with each other, it helps reinforce the need for better public education about Lyme. The resulting improved knowledge about Lyme disease in the general population might be related to improvement in attitudes and behaviors toward those with Lyme, which could, in turn, help ease their suffering and frustration. Education may not only improve persons' chances of preventing Lyme in themselves, but may also be related to improving the lives of others already suffering with Lyme.

5. References

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